



SPASTIC PARAPLEGIA FOUNDATION, INC  
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## **RFP GUIDELINES (Revised 2025)**

### **SUBMITTAL DEADLINE: August 15, 2025**

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## **I. Introduction**

The Spastic Paraplegia Foundation (SPF) is pleased to announce a Request for Proposals (RFP) to accelerate research aimed at finding effective treatments and ultimately cures for Hereditary Spastic Paraplegia (HSP) and Primary Lateral Sclerosis (PLS). This initiative seeks to support cutting-edge research across three key areas: Basic Research, Clinical Trial Readiness, and Drug Repurposing. Each selected proposal will be awarded funding for two years, with a total budget of \$150,000 per award. We invite researchers, academic institutions, and biotech companies to submit proposals that align with our mission to advance scientific understanding and therapeutic options for individuals with these rare and under-studied neurodegenerative diseases.

HSP and PLS represent a significant unmet need in neurology, with limited treatment options and a lack of disease-modifying therapies. Through this funding opportunity, we hope to make substantial progress toward identifying new molecular mechanisms, advancing clinical trial preparedness, and exploring innovative drug repurposing strategies to help individuals affected by these conditions.

## **II. Research Priorities**

The Spastic Paraplegia Foundation is particularly interested in funding research proposals that fall within the following three categories:

### **1. Basic Research**

We seek proposals that focus on advancing our fundamental understanding of the underlying pathophysiology of HSP and PLS. Key areas of interest include:

- **Molecular Mechanisms:** Investigating the genetic, cellular, and molecular pathways that contribute to the onset and progression of HSP and PLS.
- **Neurodegeneration and Motor Neuron Death:** Studying the processes of motor neuron degeneration and axonal transport dysfunction in both HSP and PLS.
- **Genetic and Epigenetic Research:** Exploring the role of known causative genes and their impact on cellular function and identifying novel genes or genetic modifiers that may influence disease progression.
- **Animal Models and Disease Models:** Developing or utilizing relevant animal or cellular models to study disease mechanisms and test therapeutic approaches.
- **Biomarkers:** Identifying biomarkers that can improve diagnostic capabilities, help with disease monitoring, or serve as endpoints for clinical trials.

### **2. Clinical Trial Readiness**

Proposals in this category should focus on preparing for and advancing clinical trials for HSP and PLS. Areas of interest include:

- **Clinical Trial Design:** Developing innovative clinical trial designs, endpoints, and methodologies tailored to HSP and PLS. This includes the identification of appropriate patient populations and inclusion/exclusion criteria.

- **Natural History Studies:** Conduct studies that better characterize the natural history of HSP and PLS, including progression rates, functional decline, and disease variability.
- **Outcome Measures:** Developing and validating outcome measures (e.g., clinical scales, quality-of-life measures, biomarkers) that can be used in future clinical trials to assess disease progression and treatment efficacy.
- **Patient-Centered Research:** Research that involves patient perspectives and real-world data, to ensure that clinical trials address the true needs of the patient population.

### 3. Drug Repurposing

We seek proposals focused on identifying and testing existing drugs for repurposing as potential therapies for HSP and PLS. Key areas include:

- **Existing Drug Screening:** Identifying FDA-approved drugs that may hold promise for treating HSP or PLS based on their molecular targets, mechanisms of action, or preclinical evidence of neuroprotective effects.
- **Preclinical Validation:** Conducting in vitro or in vivo studies to validate the efficacy of repurposed drugs in models of HSP or PLS.
- **Mechanistic Studies:** Investigating the specific molecular targets and pathways through which repurposed drugs may benefit HSP and PLS.

## Research Grants

Grants up to \$75,000 per year will be awarded for one and two-year proposals. (Maximum grant of \$150,000 over two years.) Research grants may provide “seed monies” to assist investigators with new concepts, early or pilot phases of studies, or as supplemental support in ongoing investigations. We anticipate that previous studies funded by the SPF would develop into projects that may successfully attract funding from other sources. It is highly encouraged that new applicants review the previously funded research at [https://sp-foundation.org/research/research-grants\\_issued\\_between\\_2003-2020.html](https://sp-foundation.org/research/research-grants_issued_between_2003-2020.html).

## III. Eligibility

This RFP is open to a wide range of researchers, including but not limited to:

- Academic institutions, research hospitals, and universities
- Non-profit organizations with a focus on neurodegenerative diseases
- Biotechnology and pharmaceutical companies
- Independent researchers and clinical investigators

To be eligible for funding, applicants must demonstrate:

1. Relevant expertise in neurology, genetics, molecular biology, or drug discovery.
2. Experience conducting clinical or preclinical research in rare neurological diseases or a related field.
3. The ability to execute the proposed research within the timeframes and budgets outlined in the proposal.
4. A commitment to advancing HSP and PLS research and providing data to facilitate new therapeutic approaches.

## Publicity and Confidentiality

The grant application and proposal process are considered confidential and will be released only to members of the SPF Scientific Advisory Board, the SPF Research Grant Committee, and the SPF Officers and Board of Directors.

If your grant is selected to receive funding, the title and the name of the principal investigator, and his/her institution/university will be published on our website, newsletter, annual report and wherever

else the SPF feels is appropriate. SPF requests that each grant application include a title understandable by the lay public. SPF reserves the right to contact the grant recipients to obtain more information about their research that can be communicated to the foundation's community of patients and families. Successful grant recipients will be required to provide lectures and presentations at annual conferences, meetings and/or webinars, and to participate in at least one (1) SPF TALKS (zoom video meeting) with SPF membership. Communicating the impact of the research is critical to our fundraising efforts and community engagement.

If your grant is selected to receive funding, every grant applicant and/or recipient agrees that the Spastic Paraplegia Foundation, Inc., shall have the right to utilize and share the resulting research reports and information in ANY MANNER IT DEEMS FIT AND APPROPRIATE for the purposes of finding treatments, therapeutics, and/or cures for HSP and PLS, including any collaborative effort with other research and/or patient organizations. SPF will be the owner of the research work and information for which it pays or compensates any research applicant and/or any institution or corporation with which the researcher is affiliated in any capacity whatsoever. Notwithstanding the foregoing, the grant recipient will own the copyright, if applicable, in their scholarly publications pertaining to research conducted hereunder (each, a "Publication") and may exercise all rights of ownership (including further publication) with respect to such Publications. Spastic Paraplegia Foundation, Inc. shall be permitted to use reprints of any such Publications for its own purposes in a manner that is consistent with the rights of any third-party publisher.

Grant recipients are highly encouraged to provide information and patient samples collaboratively to other researchers in the field. SPF strongly encourages a cooperative effort among researchers and forming collaborations will be highly weighted in the application process. We believe bringing together diverse perspectives, skills, and strengths in this manner will increase efficiency, expedite research, and increase disease visibility.

## **IV. Proposal Submission Guidelines**

To apply for funding, submit the following documents by [submission deadline]:

1. **Project Overview:**

A concise summary of the proposed research, its goals, and how it aligns with one of the three priority research areas (Basic Research, Clinical Trial Readiness, or Drug Repurposing).

2. **Scientific Rationale:**

A detailed explanation of the scientific background and rationale for the project, including relevant preliminary data or literature.

3. **Research Plan:**

A clear, detailed research plan that includes the following:

- Specific objectives and hypotheses
- Research methods and experimental design
- Expected outcomes and potential impact
- Timeline with key milestones and deliverables

4. **Team and Expertise:**

A brief description of the research team, including key personnel, their qualifications, expertise, and roles in the project.

5. **Budget and Funding Request:**

A detailed budget, outlining all expected costs (e.g., personnel, supplies, equipment, travel, etc.) and total funding requested.

6. **Ethical Considerations:**

Information on how the research will address any ethical concerns, including patient consent, use of human subjects, or animal welfare.

7. **Collaboration and Data Sharing:**

If applicable, describe any collaborations with other institutions or organizations and how data will be shared within the scientific community.

## **V. Evaluation Criteria**

Proposals will be evaluated based on the following criteria:

1. **Scientific Merit:**

The clarity, rigor, and novelty of the research hypothesis, methods, and expected outcomes.

2. **Innovation:**

The degree to which the proposed research offers new insights or approaches to understanding or treating HSP and PLS.

3. **Feasibility:**

The practicality and achievability of the proposed project, including the experience of the research team and the proposed timeline and budget.

4. **Impact on Patient Outcomes:**

The potential for the proposed research to lead to meaningful improvements in the diagnosis, treatment, or management of HSP and PLS.

5. **Collaboration and Interdisciplinary Approaches:**

The extent to which the research fosters collaboration with other researchers, institutions, or patient advocacy groups.

## **Application/Proposal Procedure**

### **Proposal Contents Must Include:**

1. The formal title of the proposal, and a second, modified title that is understandable to the lay public and will be used by the SPF for public relations and publicity purposes.
2. Research target (HSP, PLS or both). Note that a proposal concerning the genetic aspects of PLS will be considered a PLS proposal, not a complicated HSP proposal.
3. Specific goals. Briefly indicate what specific aim(s) the research proposed in the application intends to accomplish.
4. Background and significance.
5. Research design and methods. Describe techniques and scientific approach. Include a brief description of the statistical approach, and if applicable, power or sample size calculations.
6. Facilities available and budget. Do not include indirect costs, equipment or conference expenses, or PI salary. All amounts must be in US dollars.
7. A concluding summary (a page or less of the total 8 pages) describing the big picture of how your research program has contributed, is contributing, and/or will contribute toward a broader and deeper understanding of HSP or PLS, and how your current proposal builds on the big picture and the future beyond the proposed two-year project. This can include your development of tools such as animal models, cell models, antibodies, drugs, and DNA constructs, as well as your outreach to collaborators to strengthen the impact of your work and to foster scrutiny of your ideas and your results. Particular emphasis should be placed on elucidating the mechanisms of disease, as understanding these underlying processes is essential for developing effective therapeutic strategies. Please also include a description of how you have and will leverage SPF funding toward NIH or other funding, and how your efforts address the short-term and/or long-term priorities of the patient community.

8. Curriculum vitae/biographical sketch and bibliography (not included in the 8-page limit).

## **Proposal Page Limit**

Proposals shall be no more than 8 pages long (excluding CV/ bio sketch and bibliography).

## **Proposal Submission**

Email [Research@SP-Foundation.org](mailto:Research@SP-Foundation.org) to submit application, proposal, attachments, and/or other supporting documentation. If you have not received an acknowledgment of your submission within two business days, please re-submit the proposal.

All applications will be reviewed by the SPF's Scientific Advisory Board (SAB) and/or SPF Board of Directors. Applications will be evaluated and ranked for scientific merit. The Board of Directors will strongly consider recommendations from its SAB in making its final funding decisions.

Funding decisions will be based on the ranking assigned to each proposal, and the amount of available funds. HSP and PLS proposals will not compete against each other. Each proposal will be reviewed individually and may be subject to further stipulations.

Funding decisions will be announced to applicants by email from the SPF Board of Directors. Researchers receiving grant approval will be required to execute a contract/Research Grant Agreement (RGA) with the SPF and will be required to provide interim and final progress reports as outlined in the RGA.

## **VI. Terms and Conditions**

By submitting a proposal, applicants agree to comply with all terms and conditions outlined by the Spastic Paraplegia Foundation, including data sharing, intellectual property rights, and the ethical conduct of research.

We look forward to receiving your proposals and working together to advance the science and treatment of Hereditary Spastic Paraplegia and Primary Lateral Sclerosis.

### **Research Grant Agreement Overview**

The RGA will summarize the payment and reporting schedule. The RGA includes attestation exhibits that must be completed by the primary researcher and a financial officer authorized to commit the researcher's institution to a grant. Progress reports are required for interim payments and final reports (including a financial report detailing the use of the funds as well as a final clinical report) are required for the final payment.

### **Publications**

All manuscripts, publications, papers, posters, and exhibits by an SPF Research Grant recipient, based on work supported by an SPF grant, must carry a credit line to the Spastic Paraplegia Foundation, Inc.

A copy of manuscripts, publications, papers or posters must be submitted to the SPF when a paper or poster by an SPF Research Grant recipient is published or presented before a scientific or patient advocate organization based on work supported by an SPF grant award.

A brief, final report must be submitted to the SPF within 60 days of the end of the grant period, which will be published on the SPF website, in the SPF Annual Report, and wherever else deemed

appropriate. It must be written so that the average layperson can comprehend and appreciate the value of the research. The SPF seriously considers its responsibility in reporting to its membership on the handling and use of their contributions.

## Further Information

- Funding can be used to cover expenses such as technical assistance, supplies, and small equipment.
- Funding cannot be used to cover overhead, equipment or conference expenses, or other indirect costs.
- Clinical drug trials must meet the requirements established by the Food and Drug Administration (FDA).
- If a study involves humans, copies of the Informed Consent and the Institutional Review Board (Ethics Committee) approvals are required in the English language from each site involved in the study before payment. This is a requirement within the RGA.
- If a study involves human gene therapy, copies of the NIH Recombinant DNA Advisory Committee (RAC) review or waiver of review are required in the English language. This is a requirement within the RGA.
- Grant recipients may be asked to serve on our Scientific Advisory Board and will be expected to do so if requested.
- Grants are intended to help investigators explore complex challenges, new concepts, or to collect preliminary data that may lead to a larger-scale proposal. Proposals from new, young investigators are encouraged.
- Proposals are expected to be compliant with the two-year grant period as well as the requested budget.
- Proposals that demonstrate an awareness that experimental results sometimes do not turn out as expected—and a fallback plan—are encouraged.
- Novel ideas and approaches, and a high degree of relevance or applicability to HSP/PLS are preferred.
- All proposals, exhibits, progress reports, and any other attachments, thereto shall be provided to the SPF in the English language.
- Questions or inquiries may be directed to [Research@SP-Foundation.org](mailto:Research@SP-Foundation.org).